

Multiple Sclerosis Task Force

Final Report

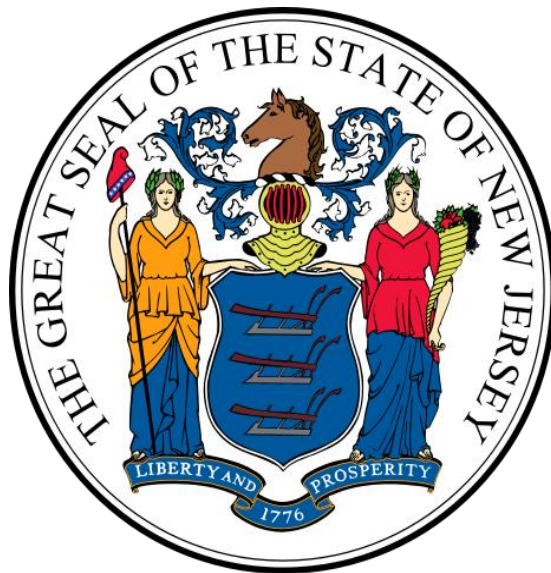


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Executive Summary

The New Jersey Legislature found that it is in the public interest for the State to establish a Multiple Sclerosis (MS) Task Force in order to identify and address the unmet needs of persons with MS, and develop ways to enhance their quality of life. On January 5, 2012, Governor Chris Christie signed and established the New Jersey Multiple Sclerosis (MS) Task Force pursuant to P.L. 2011, c. 157 (Appendix A). The purpose of the Task Force is to make recommendations that will evolve into seamless strategies to be implemented by public and community-based entities to identify and address the unmet needs of persons living with MS. Implementation of the strategies recommended by the Task Force will result in enhancement of the quality of life for persons living with MS by maximizing their productivity and independence; address their emotional, social, and vocational challenges; and providing greater access to available treatments and other therapeutic options.

Multiple Sclerosis, or MS, is a chronic condition that affects the central nervous system (CNS): the brain, spinal cord and optic nerves. Persons living with MS face many emotional, social and vocational challenges. Reducing the burden and impact of chronic disease and disability, including MS, requires strategies that work, and changes that will have a significant impact in helping individuals achieve their optimum health potential.

The MS Task Force Report identifies gaps in services and recommends comprehensive strategies to meet identified priorities to address unmet needs unique to persons living with MS in New Jersey. The Task Force formed four workgroups that adhere to the Centers for Disease Control and Prevention Chronic Disease Promising Practices Framework. The four domains outlined by the CDC provided the Taskforce a framework for the planning process: 1) Community - Clinical Linkages; 2) Health Systems Interventions; 3) Environmental Strategies; and 4) Epidemiology, Surveillance and Evaluation. Each workgroup reviewed and identified existing challenges faced by persons living in New Jersey with MS and formulated recommendations to address these challenges. The Task Force focused on policy recommendations to improve access to: quality health care, symptom-management medications, multiple sclerosis disease-modifying therapies, adaptive devices, transportation, and housing. It also made recommendations to educate persons living with MS and their families regarding available resources.

To ensure transparency and communicate the actions of the Task Force, a web page was added to the New Jersey Department of Health website. The web address is: www.state.nj.us/health/fhs/mstaskforce/index.shtml. Minutes of Task Force meetings and linkages to resources for persons living with MS and their families are included on the site.

The Task Force, after thorough deliberations, has made recommendations to maximize productivity and independence for those New Jersey residents living with MS and to ensure that persons with MS have access to varied treatments and therapeutic options that can have a positive impact on their lives.

Introduction

Multiple Sclerosis (MS) is a chronic, often disabling disease that attacks the central nervous system, which is comprised of the brain, spinal cord, and optic nerves. It is a disease in which the body, through its immune system, launches a defensive and damaging attack against its own tissues. MS damages the nerve-insulating myelin sheath that surrounds and protects the brain. The damage to the myelin sheath slows down or blocks messages between the brain and the body. Most people experience their first symptoms of MS between the ages of 20 and 40. According to the North American Research Committee on Multiple Sclerosis (NARCOMS), between 350,000 and 500,000 people in the United States are diagnosed with MS, and more than two million individuals live with the disease worldwide. More than twice as many women as men have MS. MS is more common in Caucasians and people of Northern European descent, but people from all backgrounds can be diagnosed with MS.

According to the National Institute for Neurological Disorders, the course of the disease varies greatly from person to person. It is impossible to predict the severity or progression in any given individual. To better develop appropriate management plans, MS is divided into four classifications:

- Relapsing-Remitting - clearly defined attacks lasting from days to weeks, with full recovery or with some remaining neurological symptoms and deficits upon recovery. Periods between relapses are stable and absent of disease progression. This is by far the most common form of the disease.
- Secondary-Progressive – begins initially with a relapsing-remitting course that becomes consistently progressive and includes occasional relapses and minor remission. Deficits are accumulated without recovery between attacks.
- Primary-Progressive – progression of level of disability from the onset without any distinct relapses or remissions. Temporary, minor improvements may be experienced.
- Progressive-Relapsing – clear progression in disability level from the onset, but also clear acute relapses that may or may not include memory.

There are two chapters of the National Multiple Sclerosis Society that serve New Jersey. The Multiple Sclerosis Society - Metro Chapter serves central and northern New Jersey and the Multiple Sclerosis Society - Greater Delaware Valley Chapter serves southern New Jersey and Pennsylvania. The National Society and its chapters help people affected by MS by funding cutting-edge research, driving change through advocacy, facilitating professional education, and providing programs and services that help people with MS and their families move their lives forward. Service available to persons living with MS in New Jersey through the MS Society Chapters include social/emotional support, employment, insurance and financial planning, MS education, financial assistance, and health/wellness information. In addition, the Multiple Sclerosis Association of America (MSAA) is a national, nonprofit organization dedicated to improving lives today. MSAA provides ongoing support and direct services to individuals with MS, their families, and their care partners. MSAA is headquartered in Cherry Hill, New Jersey.

Persons living with MS in New Jersey also have access to comprehensive MS treatment centers. There are five centers in New Jersey that are members of the Consortium of MS Centers, and as such go through a voluntary certification process to ensure that center personnel have knowledge in the specialization of MS care. This certification provides formal recognition that is necessary to provide optimal care to those individuals and families living with MS. Additionally, the MS Society - Metro Chapter and Greater Delaware Valley chapters maintain county-level listings of physicians, nurses, physical therapists and other healthcare practitioners who have experience treating persons with MS in the State. Resource information can be found at <http://www.nationalmssociety.org/Chapters/NJM> and <http://www.nationalmssociety.org/Chapters/PAE>.

The six centers that are part of the Consortium of MS Centers in New Jersey are:

- Kessler Foundation Research Center, West Orange, NJ
- Linda E. Cardinate MS Center at CentraState, Freehold, NJ
- Multiple Sclerosis Center at Holy Name Medical Center, Teaneck, NJ
- Multiple Sclerosis Diagnostic and Treatment Center, Rutgers/NJ Medical School, Newark, NJ
- Robert Wood Johnson Center for MS, New Brunswick, NJ
- Barnabas Health Multiple Sclerosis Comprehensive Care Center, Livingston, NJ

Additionally, the MS Center at Rowan University, School of Osteopathic Medicine is recognized as providing quality, comprehensive care to persons living with MS in southern New Jersey.

The Consortium of MS Centers in Philadelphia and New York also serve New Jersey residents.

MS Task Force Composition

The Task Force was comprised of 14 members designated by P.L 2011, c.157 as follows: the Commissioners of Health and Human Services, or their designees, who serve ex officio; eight public members, who were appointed by the Governor as follows: two neurologists licensed to practice medicine in this State; one person upon the recommendation of the National Multiple Sclerosis Society-New Jersey Metro Chapter; one person upon the recommendation of the National Multiple Sclerosis Society-Greater Delaware Valley Chapter; two persons who represent agencies that provide services or support to individuals with MS in this State; two persons who have MS; and four public members with demonstrated expertise in issues relating to the work of the task force, one each appointed by the President of the Senate, the Senate Minority Leader, the Speaker of the General Assembly, and the Assembly Minority Leader.

The members are:

Stephanie Hunsinger, Chair
Manager of Advocacy Programs
National Multiple Sclerosis Society
New Jersey - Metro Chapter

Robin Walton, Vice-Chair
Vice-Chair, Multiple Sclerosis Task Force
Vice President for Community and Government Affairs
Thomas Edison State College
Trenton, NJ

Kristen E. Polovoy, Esq., Secretary, Non- Voting Consultant
Consultant on the Multiple Sclerosis Task Force
Montgomery, McCracken, Walker & Rhoads, LLP

Allison Averill, M.D.
Director, NeuroRehabilitation Services
Kessler Institute for Rehabilitation
Livingston, NJ

Susan A. Barber
Delaware Valley Government Relations
Multiple Sclerosis Society of Greater Delaware Valley

Timothy L. Barnes, Esq.
Member National Board of Directors of National Multiple Sclerosis Society
Attorney at Porzio, Bromberg & Newman, P.C.
Morristown, NJ

Donald A. Barone, D.O.
Neurologist
Rowan University, School of Osteopathic Medicine
Stratford, NJ

Caroline Bogart, M.S.N.
Nurse Executive and Chief Operating Officer
Barnabas Health Care System – Barnabas Health Outpatient Centers
Livingston, NJ

Stuart D. Cook, M.D.
Neurologist
Rutgers - NJ Medical School
Newark, NJ

Lee B. Kushner
Co-Chair, Musical Moments for MS

Krupa Pandey, M.D.
Neurologist
Barnabas Health Care System – Multiple Sclerosis Comprehensive Care Center
Livingston, NJ

Earnestine Smith
Advocate, Union County

The Honorable Charlotte Vandervalk
Former Assemblywoman, Bergen County

Ex-Officio Members:

Joseph M. Amoroso
Director, Division of Disability Services
New Jersey Department of Human Services

Melita J. Jordan, CNM, MSN, APRN C
Director, Community Health and Wellness
Division of Family Health Services
New Jersey Department of Health

Multiple Sclerosis Task Force meetings were held on the following dates:

Date:	Location:	Time:
December 12, 2012	New Jersey Medical Society in Lawrenceville, NJ	9:30 am - 11:30 am
January 14, 2013	New Jersey Medical Society in Lawrenceville, NJ	9:30 am - 11:30 am
February 14, 2013	New Jersey Medical Society in Lawrenceville, NJ	9:30 am - 11:30 am
April 11, 2013	New Jersey Medical Society in Lawrenceville, NJ	9:30 am - 11:30 am
September 25, 2013	New Jersey Medical Society in Lawrenceville, NJ	9:30 am - 11:30 am
November 6, 2013	Teleconference	
June 9, 2014	Thomas Edison State College, Trenton, NJ	9:30 am - 12:00 pm

Minutes of the meetings are available at www.state.nj.us/health/fhs/mstaskforce/index.shtml.

The Task Force was entitled to call in assistance and avail itself of the services of the employees of any State, county, or municipal department, board, bureau, commission or agency as it may require and as may be available to it for its purposes. Consequently, on July 24, 2013, the MS Task Force held a collaborative panel discussion with representatives of New Jersey State Departments not serving on the Task Force. The MS Task Force would like to thank Ronald C. Rak, JD, President and CEO and Jay Jimenez, Vice President of Governmental Affairs at Saint Peter's Healthcare System for hosting the multiagency panel discussion. See Appendix B for a list of State Department Representatives.

The recommendations reflect the consensus of the appointed members of the Task Force. Some of the recommendations would require additional authority or other administrative or legislative change. The recommendations expressed in this report do not necessarily reflect the views or policy of any state agency.

New Jersey MS Task Force Findings and Recommendations:

Community- Clinical Linkage ensures that communities support and clinics refer patients to programs that improve management of chronic conditions.

There is an array of publicly supported services and programs that may assist persons living with MS, and their families, to help them cope with the challenges of daily living. Persons living with MS and their families must have easy access to relevant information and resources available within their communities.

Recommendation: *The MS Website currently located on the Department of Health (DOH) website should remain as a permanent fixture on the State of New Jersey, DOH website. <http://www.state.nj.us/health/fls/mstaskforce/pub.shtml>. The website should include:*

- *Relevant links to state and federal service and resources*
- *A listing of or linkage to recognized/qualified MS Centers in New Jersey, mental health, pharmaceutical assistance, durable adaptive devices, housing and transportation resources*
- *Information and linkage to relevant MS research and clinical trials being conducted in New Jersey*
- *The deliberations and recommendations of the MS Task Force by posting the Report*

New Jersey's 211 system provides assistance to callers in finding state or local health and human service resources to address urgent needs or everyday concerns 24/7. The 211 system has resources to address:

- Basic Human Needs Resource, such as food banks, clothing closets, shelters, rental assistance, and utility assistance
- Support for Seniors and Persons with Disabilities, such as adult day care, congregate meals, Meals on Wheels, respite care, home health care, transportation, and homemaker services
- Support for Children, Youth and Families, such as childcare, after school programs, Kids Care (health insurance programs), family resource centers, summer camps and recreation programs, mentoring, tutoring, and protective services
- Physical and Mental Health Resources, such as health insurance programs, Medicaid and Medicare, maternal health, Family Care, medical information lines, crisis intervention services, support groups, counseling, drug and alcohol intervention and rehabilitation
- Employment Supports: financial assistance, job training, transportation assistance, and education programs

The Division of Disabilities Services, through the Office of Information and Assistance Services, Department of Human Services (DHS) provides information and resources and also acts as a single point of entry for callers to access the State's human services system. This Office also can assist New Jersey residents with any disability-related need.

The NJ Statewide Respite Care Program through DHS provides respite care services for elderly and functionally impaired persons age 18 and older to relieve their unpaid caregivers of stress arising from the responsibility of providing daily care. A secondary goal of the program is to provide the support necessary to help families avoid making nursing home placement of their relatives.

In addition, New Jersey receives federal funding support through the Lifespan Respite Care Act (P.L. 109-442) to assist family caregivers in accessing affordable and high-quality respite care. Specifically, this law authorizes:

- Lifespan respite programs at the state and local levels
- Planned and emergency respite for family caregivers
- Training/recruitment of respite workers and volunteers
- Provision of information to caregivers about respite/support services
- Assistance for caregivers in gaining access to such services
- Establishment of a National Resource Center on Lifespan Respite Care

Health Systems Interventions improve the effective delivery and use of clinical and other preventive services to prevent disease, detect disease early, reduce or eliminate risk factors, and mitigate or manage complications.

For persons living with MS, access to comprehensive quality health care may be challenging. Persons living with MS have indicated difficulty in locating accessible healthcare services including dental, gynecological, and mammography services throughout the State.

The Americans with Disabilities Act of 1990 (ADA) is a federal civil rights law that prohibits discrimination against individuals with disabilities in everyday activities, including medical

services. Section 504 of the Rehabilitation Act of 1973 (Section 504) is a civil rights law that prohibits discrimination against individuals with disabilities on the basis of their disability in programs or activities that receive federal financial assistance, including health programs and services. These statutes require medical care providers to make their services available in an accessible manner. Private hospitals or medical offices are covered by Title III of the ADA as places of public accommodation in accordance with federal regulations 28 CFR Part 36, Subpart D, for Title III entities.

Recommendation: *MS Advocates and professional medical organizations should increase awareness of ADA requirements of professionals so they may better serve the disabled population.*

Recommendation: *Encourage healthcare providers to make physical modifications to offices/facilities or to purchase modified equipment that can accommodate persons with MS or other patients with disabilities.*

The American Academy of Neurology, MS Council for Clinical Practice, issues guidelines for use of disease-modifying drugs and symptom management medications. These medications may help to reduce inflammation in the central nervous system (CNS), reduce the frequency and severity of MS attacks and the numbers of lesions in the CNS, and may slow the progression of disease-modifying disability. Overall prescription cost is high for those living with MS in terms of both disease-modifying therapies (DMTs) and symptom-management medications. In recent years, numerous effective DMTs for MS have become available, giving neurologists and persons living with MS a variety of treatment options for slowing disease activity and managing symptoms.

There is general consensus within the Task Force that helping those living with MS manage their disease now, with appropriately prescribed medications, in order to avoid or delay long-term disability will, over time, reduce the economic burden on the State and on society and enhance the quality of life of the person living with MS. Anecdotally, the Task Force discussed some of the challenges faced by persons living with MS. One of those challenges was denial of appropriate medications by a patient's insurance carrier. Denial of prescription drug coverage to help MS patients manage their symptoms compromises a person's ability to remain in the workforce and to retain their current levels of health, wellness, and functioning.

Recommendation: *Insurance companies should consider consulting Board-certified neurologists to review any appeal of prescription drug coverage for symptom-management medications, and US Food and Drug Administration (FDA)-approved multiple sclerosis disease-modifying therapies.*

Recommendation: *With respect to medications prescribed by New Jersey residents' physicians to manage their MS symptoms, as well as with respect to MS disease-modifying medications prescribed by New Jersey residents' physicians, the New Jersey Department of Banking and Insurance should consider issuing regulations that prohibit*

health insurance carriers that insure New Jersey residents from imposing prescription copays for brand medications that are higher than the plans' copays for generic medications.

The availability and financial accessibility of High End Mobility Devices and other assistive technology allow individuals with MS to function more independently and allow many to remain in the workforce, therefore being productive tax-paying citizens. In addition, ensuring access to assistive technology may increase patient and productivity, decrease use of mental health services, and delay nursing home placement. High End Mobility Devices help to maintain a person's mobility, maximize stability, and ensure their safety. A person with MS may qualify for Social Security Disability Insurance (SSDI) benefits; however, even after qualifying, a person is not eligible for Medicare benefits until they have received SSDI benefits for 24 months. In comparison, persons with permanent kidney failure requiring regular dialysis or a transplant or have amyotrophic lateral sclerosis (Lou Gehrig's disease) may qualify for Medicare almost immediately. The 24 month waiting period for Medicare, while receiving SSDI benefits is a significant barrier to obtaining access to equipment, specifically wheelchairs for persons with MS.

Recommendation: *MS advocates should campaign for federal legislation that would include multiple sclerosis as a disease that would qualify for Medicare almost immediately after SSDI benefits are approved.*

Recommendation: *The Division of Disability Services (DDS), DHS, should continue to provide publicly supported subsidies for the purchase of High End Mobility Devices or other assistive technology for persons living with MS to ensure access to equipment like wheelchairs.*

Everyone benefits from regular exercise to maintain health and wellness. Research studies suggest regular exercise may contribute to emotional well-being. It is especially important for persons living with MS to improve cardiovascular health, strength and endurance. Exercise can help relieve MS-related fatigue and manage spasticity. Persons living with MS should consult with their physician, nurse, or a physical therapist before starting an exercise program. Access to regular exercise through a health club membership may enhance the health and well-being of persons living with MS and prolong their employability and productivity.

Recommendation: *Persons living with MS should be encouraged to participate in wellness programs at health clubs or in nontraditional settings, i.e., rehabilitation centers or hospital wellness programs to promote wellness.*

Recommendation: *Support and reinforce healthy behaviors statewide in worksites and communities.*

Transportation and Housing

All persons should be able to access employment, education, health care, and community life. Handicapped-accessible public transportation services or modifications to a personal vehicle

allows persons living with MS to live independently within their communities. Transportation access issues should be addressed so persons living with MS can continue living productively by going to work, accessing healthcare, shopping or engaging in other community activities.

However, public transportation services are often not accessible to individuals with MS outside of New Jersey's urban centers. New Jersey Transit has an Access Link Program that mirrors the public transportation routes within the State. Access Link provides vital service for persons living with MS and other disabilities. Access Link service is only available if there is fixed route bus service available in the geographic area. If there is no fixed route bus service, Access Link is not available.

DDS administers the Medicaid home and community-based services (HCBS) waiver. Environmental/vehicular accessibility adaptations are a covered service under the waiver. Effective July 1, 2014, New Jersey's Home and Community Based Services are no longer disability-specific and are now available to individuals with MS.

Recommendation: *Explore with New Jersey Transit (NJT) expanding the scope and geographic accessibility of Access Link to areas of the State not currently serviced.*

Recommendation: *Explore with (NJT) a policy change that would allow persons with disabilities to enroll in Access Link without physically going to the Access Link office. Determine whether Access Link would accept the signature of an attending physician to verify need for Access Link.*

Recommendation: *Explore new resources to assist with vehicular accessibility adaptation for persons living with MS who do not qualify for the Medicaid waiver.*

Recommendation: *Educate the general public as to handicap parking laws. Specifically:*

- *Display videos/materials in the Motor Vehicle Commission sites for the population to learn about accessible parking*
- *Educate physicians on the disability registration form and use of the disability handicap placard*

Living as independently as possible and being part of a community is a goal shared by those living with MS and others with disabilities. There is a lack of accessible homes to accommodate people with disabilities, including those with MS. Persons living with MS may find the pursuit of accessible housing daunting. Accessible housing can also be very costly to rent or purchase. Accessible housing must be addressed in terms of life phases. Housing for people living with MS must be thought of as a continuum, since at some point the health of persons will decline. By ensuring that accessible housing is both available and affordable within a community helps those living with MS delay or avoid nursing home placement.

In 2005, the Special Needs Housing Trust Fund was established under the auspices of the New Jersey Housing and Mortgage Finance Agency (NJHMFA). The legislation recognized the need to create permanent supportive housing and community residences as alternatives to institutionalization or homelessness for those who would benefit from these programs.

P.L. 2005, c. 163 authorized up to \$200 million for the Trust Fund. Due to the overwhelming success of the Fund, the NJHMFA suspended the intake of applications for the program on October 31, 2011.

Most state and federal assistance for housing or home modifications are only accessible to those living at or below the federal poverty level (FPL) to a maximum of 250% of FPL. This equates to between \$15,730 ($\geq 100\%$ FPL) to \$39,325 (250% FPL) annually for a family of two. See Appendix C for 2014 Federal Poverty Guidelines.

Recommendation: *The Special Needs Housing Trust Fund should be reauthorized to support housing.*

Recommendation: *Explore options to sustain or expand assistance for the home modification program to serve those living above 250% FPL to 500% FPL.*

Persons living with MS may experience weakness, fatigue, visual disturbances, and other symptoms that can become aggravated and temporarily worsen when their body temperature rises. Although heat does not actually make MS worse, it does alter the passage of nerve impulses, causing a feeling of weakness, especially in the limbs. The Multiple Sclerosis Foundation offers a Cooling Program that can assist in procuring Environmental Control Systems. Patients with MS can also use New Jersey's Home Energy Assistance Program that helps very low-income residents with their heating and cooling bills. The Low Income Home Energy Assistance Program (LIHEAP) is designed to help low-income families and individuals meet home heating and medically necessary cooling costs. To be eligible for LIHEAP benefits, the applicant household must be responsible for home heating or cooling costs, either directly or included in the rent, and have gross income at or below 200% of the FPL.

Recommendation: *Explore funding sources that will pay or offset the cost of installing heating and cooling systems for individuals with MS.*

DOH's Epidemiology, Surveillance, and Evaluation program gathers, analyzes and disseminates data to inform, prioritize, deliver, and monitor programs and population health.

There are no federal or State requirements to report MS. Therefore, the incidence and prevalence of MS is not consistently tracked. According to the North American Research Committee on Multiple Sclerosis, between 350,000 and 500,000 people in the United States are diagnosed with MS, and more than two million individuals live with the disease worldwide. More than twice as many women as men have MS. MS is more common in Caucasians and people of Northern European descent, but people from all racial and ethnic backgrounds can be diagnosed with MS.

The National Multiple Sclerosis Society - New Jersey Metro Chapter and Delaware Valley Chapter have records of approximately 13,428 residents within the State who are registered with the Society. The data only reflects those who are registered members of the Society, and is not an accurate accounting of all people living with MS in New Jersey.

Although data is not specific to persons living with MS, County Health Rankings, published through a collaboration of the Robert Wood Johnson Foundation (RWJF) and the University of Wisconsin Population Health Institute (UWPHI), measure the health of nearly every county in the nation. Twenty-nine factors are used to calculate the rankings including the rate of premature deaths; behaviors like percentages of residents who smoke, drink excessively or are physically inactive; accessibility and quality of clinical care; social and economic factors like the unemployment rate and the percentage of children living in poverty; the physical environment, including air and water quality; and housing and transportation issues. Many of these factors are relevant to persons living with MS. See Appendix C for the County Health Rankings and maps ranking health outcomes and health factors.

Recommendation: *State agencies could identify existing state level data sources, that could assist in determining the prevalence of New Jersey residents who are presently living with MS.*

Recommendation: *Explore resources to develop a module on MS and include in the Behavioral Risk Factor Surveillance survey to estimate the prevalence of MS in New Jersey.*

Research

Research funding from the National Institutes of Health (NIH), a foundation of New Jersey's biosciences industry, is essential for creating cures and discovering preventive measures and treatments. NIH has helped make significant progress in understanding MS lesions and analyzing how the immune system responds to different stimuli.

New Jersey is known as “The Medicine Chest of the World.” The State has the nation’s highest concentration of scientific professionals, with 126,000 life sciences/biopharma workers statewide. Seven of the world’s 20 largest pharmaceutical leaders are located in New Jersey, contributing to its \$24 billion industry. The State’s largest industry supports the highest concentration of professionals in science-related fields. New Jersey has invested in cancer, spinal cord, brain injury, and autism research by providing grants to New Jersey research institutions. New Jersey's investment in research has resulted in millions of federal and private dollars being leveraged to support research in the State. As an example, over a 25-year period (1983-2008) New Jersey's State funding for cancer research leveraged \$350 million in federal NIH or private pharma research funding for New Jersey research institutions. Based on the success of the State's past and current investment in research, an investment in MS research could incentivize and expand MS research in New Jersey and lead to improved care for persons living with MS.

Recommendation: *Establish a funding mechanism to support MS research in New Jersey. Create a matching grant program for MS research designed to leverage federal or private research dollars.*

Opportunities:

The MS Task Force seeks to collaborate with State government to ensure that New Jersey residents living with MS are getting the care and treatment they need.

Recommendation: *The New Jersey MS Task Force should be reconstituted to Serve as a biannual advisory body to accomplish the following:*

- *Review and assess accountability of the implementation of Task Force recommendation in the report*
- *Determine how to communicate and effectively collaborate with public and private entities to provide an integrated approach to services, guidance, and resource allocation to meet the needs of individuals with MS*

Recommendation: *State and/or local governmental agencies should appoint or include representation of persons living with or knowledgeable of MS to governmental councils, commissions, task forces, advisory boards etc. that focus on persons living with disabilities or chronic diseases.*

Recommendation: *The Department of Human Services, Division of Disability Services should consider filling any vacancies on the DDS Health and Wellness Advisory Council with a person living with or knowledgeable of MS.*

Resources:

Web addresses that are excellent resources for the residents of New Jersey are as follows:

New Jersey Programs:

A few of the local chapters of the National MS Society offer financial assistance to NJ residents -

<http://www.nationalmssociety.org/chapters/pae/programs--services/services/financial-assistance/index.aspx>

<http://www.nationalmssociety.org/chapters/njm/programs--services/financial-assistance/index.aspx>

<http://www.state.nj.us/humanservices/doas/home/paaddetail.html>

<http://www/state.nj.us/humanservices/dds>

Nationwide Programs:

American Academy of Neurology <https://www.aan.com>

Chronic Disease Fund <https://patientsandpros.cdfund.org/>

The Assistance Fund (also offers financial assistance for insurance premiums for MS patients)

<http://theassistancefund.org/patient-services/#>

NORD (Multiple Sclerosis Related Acute Exacerbation) <http://rarediseases.org/patients-and-families/patient-assistance>

PAN <https://www.panfoundation.org/multiple-sclerosis>

Manufacturer Programs:

The Multiple Sclerosis Association of America has a great list: <http://www.mymsaa.org/about-ms/sources/>

APPENDIX

A

CHAPTER 157

AN ACT establishing the New Jersey Multiple Sclerosis Task Force.

BE IT ENACTED *by the Senate and General Assembly of the State of New Jersey:*

1. The Legislature finds and declares that:
 - a. Multiple sclerosis (MS) is a chronic, often disabling disease that attacks the central nervous system, which is comprised of the brain, spinal cord, and optic nerves. It is a disease in which the body, through its immune system, launches a defensive and damaging attack against its own tissues. MS damages the nerve-insulating myelin sheath that surrounds and protects the brain. The damage to the myelin sheath slows down or blocks messages between the brain and the body;
 - b. Most people experience their first symptoms of MS between the ages of 20 and 40. MS symptoms can include visual disturbances, muscle weakness, trouble with coordination and balance, sensations such as numbness, prickling or “pins and needles,” and thought and memory problems. MS patients can also experience partial or complete paralysis, speech impediments, tremors, dizziness, stiffness and spasms, fatigue, paresthesias, pain, and loss of sensation;
 - c. The cause of MS remains unknown; however, having a first-degree relative, such as a parent or sibling, with MS significantly increases a person’s risk of developing the disease. According to the National Institute of Neurological Disorders and Stroke, it is estimated that there are approximately 250,000 to 350,000 persons in the United States who are diagnosed with MS. This estimate suggests that approximately 200 new cases are diagnosed each week;
 - d. Presently there is no cure for MS. While some scientists look for therapies that will affect the overall course of the disease, others search for new and better medications to control the symptoms of MS without triggering intolerable side effects; and
 - e. Therefore, it is in the public interest for the State to establish a Multiple Sclerosis Task Force in order to identify and address the unmet needs of persons with MS, and develop ways to enhance their quality of life.

2. a. There is established the New Jersey Multiple Sclerosis Task Force in the Department of Health and Senior Services.

The purpose of the task force shall be to:

- (1) develop strategies to identify and address the unmet needs of persons with MS in order to enhance the quality of life of persons with MS by maximizing productivity and independence, and addressing emotional, social, and vocational challenges of persons with MS; and

(2) develop strategies to provide persons with MS greater access to various treatments and other therapeutic options that may be available.

b. The task force shall consist of 14 members as follows:

(1) the Commissioners of Health and Senior Services and Human Services, or their designees, who shall serve ex officio;

(2) eight public members, who shall be appointed by the Governor as follows: two neurologists licensed to practice medicine in this State; one person upon the recommendation of the National Multiple Sclerosis Society-New Jersey Metro Chapter; one person upon the recommendation of the National Multiple Sclerosis Society-Greater Delaware Valley Chapter; two persons who represent agencies that provide services or support to individuals with MS in this State; and two persons who have MS; and

(3) four public members with demonstrated expertise in issues relating to the work of the task force, one each to be appointed by the President of the Senate, the Senate Minority Leader, the Speaker of the General Assembly, and the Assembly Minority Leader. Vacancies in the membership of the task force shall be filled in the same manner provided for the original appointments.

c. The task force shall organize within 120 days following the appointment of a majority of its members and shall select a chairperson and vice-chairperson from among the members. The chairperson shall appoint a secretary who need not be a member of the task force.

d. The public members shall serve without compensation, but shall be reimbursed for necessary expenses incurred in the performance of their duties and within the limits of funds available to the task force.

e. The task force shall be entitled to call to its assistance and avail itself of the services of the employees of any State, county or municipal department, board, bureau, commission or agency as it may require and as may be available to it for its purposes.

f. The task force may meet and hold hearings as it deems appropriate.

g. The Department of Health and Senior Services shall provide staff support to the task force.

3. The task force shall report its findings and recommendations to the Governor, and to the Legislature pursuant to section 2 of P.L.1991, c.164 (C.52:14-19.1), along with any legislative bills that it desires to recommend for adoption by the Legislature, no later than 12 months after the initial meeting of the task force.

4. This act shall take effect immediately and shall expire upon the issuance of the task force report.

Approved January 5, 2012.

APPENDIX

B

Collaborative Panel Discussion

The purpose of the Panel Discussion was to ascertain what publicly supported services are available to assist persons living with MS and their families/caretakers in New Jersey. Through collaboration with relevant State departments, the Task Force seeks to confront concerns regarding access to therapy, treatment, employment, and community services by integrating recommendations and strategies to advance measures that will help individuals, and their families, living with MS.

Date:	Location:	Time:
July 24, 2013	Saint Peters University Hospital, New Brunswick, NJ	9:30 a.m.–3:30 p.m.

New Jersey State Department Representation

- New Jersey Housing and Mortgage – Anthony L. Marchetta, Executive Director
- New Jersey Department of Labor and Workforce Development – Alice Hunnicutt, Representative
- New Jersey Employment and Training Commission – Kirsten Giardi, Representative
- New Jersey Department of Transportation – Melanie Armstrong, Representative
- New Jersey Department of Banking and Insurance – Neil Sullivan, Representative
- New Jersey Department of Human Services, Division of Aging Services – Luis Ortiz, Representative
- New Jersey Department of Human Services, Division of Disability Services – Joseph Amoroso, Ex-officio member, MS Task Force

APPENDIX

C

2014 POVERTY GUIDELINES

ALL STATES (EXCEPT ALASKA AND HAWAII) AND D.C.

ANNUAL GUIDELINES

FAMILY SIZE	PERCENT OF POVERTY GUIDELINE								
	100%	120%	133%	135%	150%	175%	185%	200%	250%
1	11,670.00	14,004.00	15,521.10	15,754.50	17,505.00	20,422.50	21,589.50	23,340.00	29,175.00
2	15,730.00	18,876.00	20,920.90	21,235.50	23,595.00	27,527.50	29,100.50	31,460.00	39,325.00
3	19,790.00	23,748.00	26,320.70	26,716.50	29,685.00	34,632.50	36,611.50	39,580.00	49,475.00
4	23,850.00	28,620.00	31,720.50	32,197.50	35,775.00	41,737.50	44,122.50	47,700.00	59,625.00
5	27,910.00	33,492.00	37,120.30	37,678.50	41,865.00	48,842.50	51,633.50	55,820.00	69,775.00
6	31,970.00	38,364.00	42,520.10	43,159.50	47,955.00	55,947.50	59,144.50	63,940.00	79,925.00
7	36,030.00	43,236.00	47,919.90	48,640.50	54,045.00	63,052.50	66,655.50	72,060.00	90,075.00
8	40,090.00	48,108.00	53,319.70	54,121.50	60,135.00	70,157.50	74,166.50	80,180.00	100,225.00

For family units of more than 8 members, add \$4,060 for each additional member.

MONTHLY GUIDELINES

FAMILY SIZE	PERCENT OF POVERTY GUIDELINE								
	100%	120%	133%	135%	150%	175%	185%	200%	250%
1	972.50	1,167.00	1,293.43	1,312.88	1,458.75	1,701.88	1,799.13	1,945.00	2,431.25
2	1,310.83	1,573.00	1,743.41	1,769.63	1,966.25	2,293.96	2,425.04	2,621.67	3,277.08
3	1,649.17	1,979.00	2,193.39	2,226.38	2,473.75	2,886.04	3,050.96	3,298.33	4,122.92
4	1,987.50	2,385.00	2,643.38	2,683.13	2,981.25	3,478.13	3,676.88	3,975.00	4,968.75
5	2,325.83	2,791.00	3,093.36	3,139.88	3,488.75	4,070.21	4,302.79	4,651.67	5,814.58
6	2,664.17	3,197.00	3,543.34	3,596.63	3,996.25	4,662.29	4,928.71	5,328.33	6,660.42
7	3,002.50	3,603.00	3,993.33	4,053.38	4,503.75	5,254.38	5,554.63	6,005.00	7,506.25
8	3,340.83	4,009.00	4,443.31	4,510.13	5,011.25	5,846.46	6,180.54	6,681.67	8,352.08

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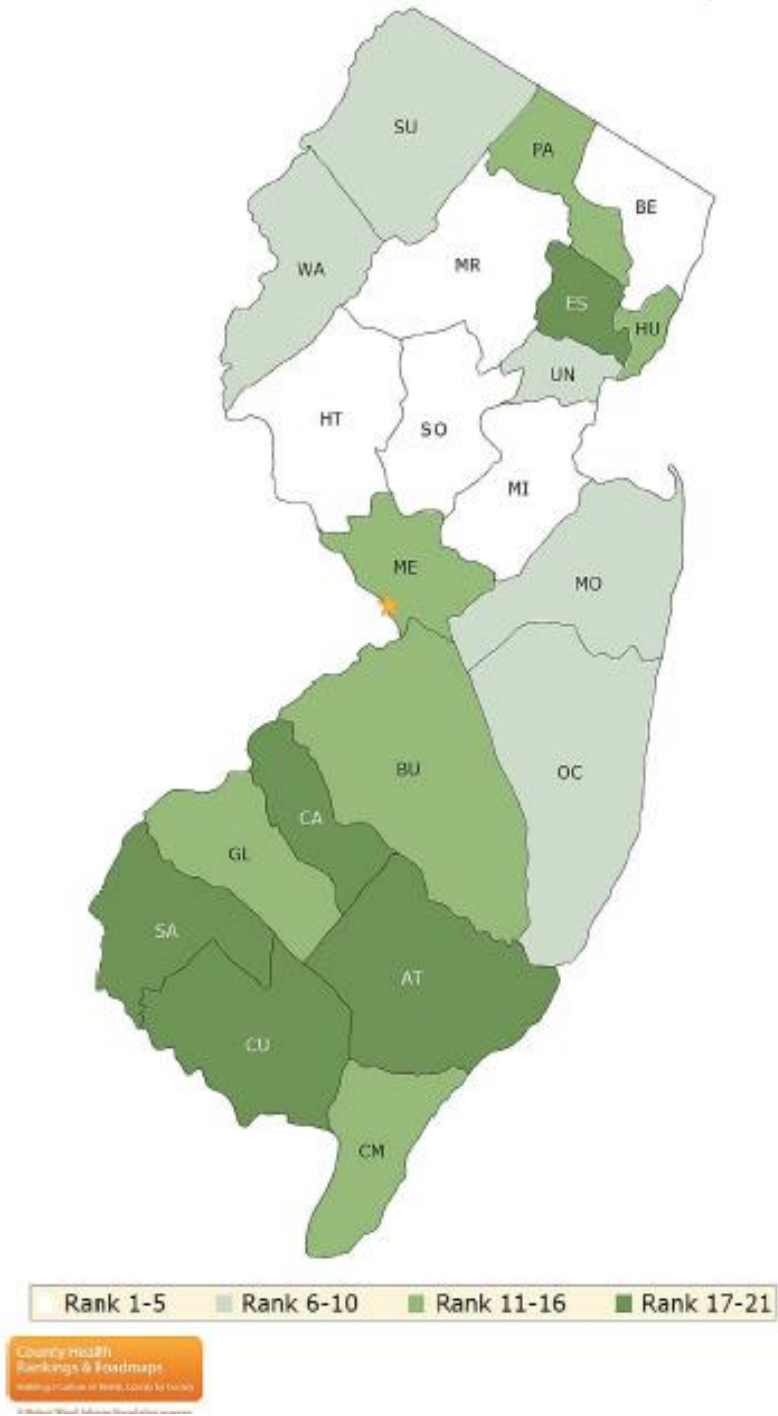
APPENDIX

D

County Health Rankings 2014

Rank	Health Outcomes	Rank	Health Factors
1	Hunterdon	1	Hunterdon
2	Somerset	2	Morris
3	Morris	3	Somerset
4	Bergen	4	Bergen
5	Middlesex	5	Monmouth
6	Monmouth	6	Middlesex
7	Ocean	7	Burlington
8	Sussex	8	Mercer
9	Warren	9	Warren
10	Union	10	Sussex
11	Burlington	11	Ocean
12	Mercer	12	Union
13	Gloucester	13	Gloucester
14	Passaic	14	Cape May
15	Cape May	15	Passaic
16	Hudson	16	Camden
17	Camden	17	Essex
18	Salem	18	Hudson
19	Atlantic	19	Atlantic
20	Essex	20	Salem
21	Cumberland	21	Cumberland

2014 Health Outcomes - New Jersey



2014 Health Factors - New Jersey

